

COMMISSION ON AGING AND END OF LIFE ISSUES

Report and Recommendations

December 31, 1997

In June 1997, the United States Supreme Court issued an opinion that, in effect, made the question of physician assisted suicide a matter for each state to decide. As a result of this decision, Executive Order 97-8 was issued on July 22, 1997, which established the Arizona Commission on Aging and the End of Life (see attached). The structure and duties of this commission included:

- Conduct research, take testimony from Arizona citizens about their family experiences, hear from qualified experts, gather the available historical, literary and other material pertaining to issues of aging and dying.
- Develop recommendations for establishing standards for the elder care industry and policy in support of families caring for elderly loved ones.
- Develop recommendations for quality medical care at the end of life and for preservation of Arizona's legal and cultural disfavor of assisted suicide and euthanasia.
- Issue its final report to the Governor by December 31, 1997.

To begin to develop recommendations in this regard, the Commission took up the subjects of hospice, pain management, education of practitioners and the public, financing, advance directives, and heard from government agencies, health professional associations, educational institutions, insurance companies, community organizations, the public and others on the matter of aging and dying.

The findings of the Commission can be summarized as follows:

HOSPICE

Hospice care is designed for people whose physician has determined they are terminally ill and for Medicare funding purposes, have six months or less to live. It was developed primarily to deal with cancer patients but is now being extended to people with AIDS and chronic conditions such as congestive heart failure and chronic obstructive pulmonary disease. Only 15 to 17% of terminally ill patients become involved with hospice. It appears that the major reasons for this are lack of public knowledge and the reluctance of some physicians to recommend this palliative care model. Palliative care is that which supports the person but does not treat the primary disease process. Good Samaritan Hospital in Phoenix is developing a program that delivers treatment along with palliative care as a modification of the hospice concept. Time will tell if this approach is more acceptable.

PAIN MANAGEMENT

Not all terminally ill patients are subjected to extreme pain but for those who are there are treatments that can be very effective in controlling the pain. The Commission determined from testimony that doctors who use narcotics for appropriate pain management had nothing to fear from either the Federal Drug Enforcement Agency or the State Board of Medical Examiners. There does appear to be a substantial lack of training for physicians in good pain management and the advances in that treatment that are available. Not all patients die in pain but for those whose pain is a problem there is little excuse for their suffering. The Commission heard testimony indicating families are often reluctant to see their loved one given large doses of narcotics for fear they will become addicted. This is, however, rarely the case.

EDUCATION

The Commission heard testimony concerning medical school education at the University of Arizona, nursing education at Arizona State University and residency training in the Phoenix area. The U of A only offers four hours of gerontology education in its undergraduate program and nothing related to pain management or palliative care. Nursing's basic education is more in line with the palliative care philosophy but graduate nurses are more interested in the high profile jobs such as the emergency room care. There are very few gerontology nurses in Arizona although the demographics seem to indicate that is where the jobs will be. Arizona has a rapidly growing population of seniors and will be second only to Florida in the percentage of our population over age 60 by the year 2010. Reimbursement for training programs for health care professionals related to our aging population is minimal and in some cases non-existent.

One bright spot is the residency training for family practice physicians which does include aspects of end of life care. However, in general little importance is given to the psycho-social needs of the patient or to their spiritual needs.

ADVANCE DIRECTIVES

Advance directives are important documents in assuring the wishes of a patient are followed. These directives may include a durable medical power of attorney naming a person to make medical decision when the patient cannot. A person may also have a "living will" in which the person's wishes related to treatment are spelled out. A third form that is an advance directive is a "do not resuscitate" order. The Commission found that these directives are not widely used and yet they provide for a person to refuse types of treatment they do not wish to have. It is felt people do not generally realize they have a right to refuse medical treatment. However, it is important that the documents be clear and unambiguous. It is also very important that these documents be part of the patient's medical record and be brought to a hospital with the patient.

FINANCING

For the senior citizen there are a number of options for health care coverage. There is the traditional Medicare, parts A and B. For those who can afford it, there are supplemental policies that pay at least a portion of the costs that Medicare doesn't. However, Medicare does not provide for long term care. Seniors too often do not realize this and fail to investigate long term care insurance well before they might need it. The earlier it is purchased the less expensive it is. Alternative coverage is available through eight managed care companies. These health plans provide more benefits than Medicare such as some coverage of prescription drugs. However, recent reports indicate that the financial support for these programs may be reduced by the Federal government.

Another concern of the Commission is the lack of funding of appropriate education for health care professionals. As one physician put it, depression is a low tech disease that does not generate much financial return, and yet it is often one of the prominent problems of the terminally ill. In addition residencies do not compensate for time spent in a nursing home or a hospice program where many of the terminally ill are cared for.

Medicare is an acute care system but as our population ages chronic disease care becomes far more important. And yet, despite its growing importance, chronic care is insufficiently recognized by Medicare and by the medical profession in general. Health care financing appears to be in need of substantial change.

IN CONCLUSION education and financing are the main needs the Commission identified for improving the care of people approaching the end of life. Education involves a wide range of needs from the health care professional to the general public and the patients themselves. Financing in both the education of the care givers and the support of the patient is a critical component for improvement of care at the end of life.

The financing issue can be broken down into two parts; those that relate to the training and education of the health care professional and the financial concerns of the patient related to the cost of care.

The Commission heard testimony emphasizing the need for professionals and the public to be willing to discuss the issues surrounding the end of life and to begin to deal with them in a realistic manner.

RECOMMENDATIONS;

The Governor's Commission on Aging and End of Life issues recognizes the singular value of each person. Therefore, the Commission proposes, first that we do all that is necessary to educate the citizens and caregivers about end-of-life issues and possibilities for care. Second, that the policy makers of this state agree to support the physical, spiritual, and financial resources necessary for all citizens to move toward the end of life without fear of intolerable pain and with assurance that their dignity will be respected and cared for at all times.

We believe the prohibition in state law against assisted suicide should be maintained.

The Commission recommends that the Arizona Medical Association, the Arizona Hospital Association and the Arizona Nurses Association make the education of the public regarding hospice care a priority of their organization. This can be done by better education and understanding by the members of these organizations of the care hospice delivers.

The Commission recommends that the education of professional health care workers in Arizona be modified to recognize the need for the understanding of palliative care, the psycho-social aspects of end of life and the dynamics of pain management. Funding should be aligned to meet these educational components both in the undergraduate level of medical and nursing education and in continuing education requirements. Hospitals, nursing homes and other health care institutions should provide substantial in service training in end of life care on a continuing basis. The public also needs education to know that they have a right to refuse medical treatment, that they should have advanced directives to assure their wishes are adhered to and to learn about alternatives such as hospice programs.

The Commission recommends a serious study of ways to improve the education of health care professionals and the public and this should include incentives where appropriate. With the advancement in technology and health care that is enabling people to live longer it is critical that we change traditional thinking regarding the end of life. This can only be done through ongoing discussion and action among health care professionals, educational institutions and the public.

The Commission believes that a state-wide conference for caregivers, primarily doctors, nurses and other health care professionals, would be an appropriate way to explore more definitive ways to improve the education and training of providers and the public about choices available to them and ways to treat the terminally ill person. The Commission requests extension for the purpose of exploring with the Robert Wood Johnson Foundation the possibilities of funding such an effort to initiate a state-wide dialogue about the issues.

The Commission did not hear from anyone who recommended physician assisted suicide. Rep. Sue Lynch, R., Prescott, did discuss her legislative bill concerning pain medication. However, in discussion the Commission felt that physicians can now do everything the bill is meant to authorize and there was some concern expressed that the ambiguous language of the bill could be interpreted to authorize physician assisted suicide if it were challenged in court. Therefore, the members of the Commission are not in support of the bill.

The Commission believes the standard of care for the elderly should provide for the dignity of the person at all times, freedom from physical, emotional and financial abuse and appropriate health care by well trained personnel.

We, the members of the Commission, appreciate having had the opportunity to be involved in this project and look forward to working on plans to implement reforms in the system to help everyone, especially our seniors, to live in good health as long as possible, to be protected from abuse, and to die with the maximum emotional and spiritual support and the appropriate medical care that every human being is entitled to.

**Governor's Commission on Aging and
End of Life Issues**

Speakers

Sept. 9, 1997	Susan Goldwater, Hospice of the Valley Alan Schafer, AHCCCS Virginia Blair, DHS Suzanne Patterson, Citizen
Sept.23,1997	Kathy Boyle, Pharmacists Association Joyce Kossick, AZ Board of Pharmacy Tom Babbick, DEA Dr. Douglas Merrill, Pain Management Specialist
Oct. 7, 1997	Dr. John T. Boyer, U of A School of Medicine David Landrith, Arizona Medical Association Fran Roberts, AZ Hospital and Health Care Assn. Chris Francis, AZAHA Mary Killeen, ASU School of Nursing Dr. James MacKenzie, Family Practice Behavioral Health
Oct. 21, 1997	Charles Arnold, Attorney Joan Johnson, ADHS Licensure – Home & Community Based Services Laura Hartgroves, ADHS Linda Palmer, ADHS Licensure – Skilled Nursing Facilities Mark Speicher, Board of Medical Examiners Anne Marie Berger, Osteopathic Physicians Board Joey Ridenour, Arizona Board of Nursing
Nov. 4, 1997	Steve Gelbart, AZ Dept of Insurance John Dollard, Blue Cross-Blue Shield Thomas Lescault, Intergroup Bob Boyajian, the Heartland Group Ward Parker, Attorney General's Office
Nov. 18, 1997	Sue Lynch, House of Representatives Sandy Bonstelle, Gerontological Nursing Chapter Debby Elliott, Care Directions Chaplain Onie Mision-Reed, Desert Samaritan Hospital Suzanne Lacavage, Center Hospice, Prescott Guy Mikkelsen, Foundation for Senior Living
Dec. 2, 1997	No speakers
Dec. 9, 1997	Joanne Lynn, M.D., George Washington University Paul E. Stander, M.D., Palliative Medicine Program, Good Samaritan Hospital Charles Daschbach, M.D., St. Joseph's Hospital

**GOVERNOR'S COMMISSION ON AGING AND
END OF LIFE ISSUES**

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Retired ASU Professor

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END OF LIFE ISSUES

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